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A “Well Kept Secret,” Identifying Facilitators and Barriers to Occupational Therapy Referral by United States Cancer Healthcare Professionals

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Under the direction of the research advisor: Katie Polo DHS, OTR, CLT-LANA

A Research Project Entitled

Title: A "Well Kept Secret," Identifying Facilitators and Barriers to Occupational Therapy Referral by United States Cancer Healthcare Professionals

Submitted to the School of Occupational Therapy at the University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

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Scoping Review

The number of people living with or beyond cancer (LWBC) is rising, from 15.5 million in this decade, to 20 million in the next (Alfano et al., 2017). Cancer survivorship is defined as the span of time between diagnosis until the end of life (Loh & Jonsson, 2016). With a survival rate of 67% overall, there is a large percentage of people who live with the side effects of cancer and medical treatments throughout their entire lifetime (Siegel et al., 2020).

A diagnosis, as well as treatment for cancer, can lead to a range of short-term, long-term, and late-onset symptoms (Alfano et al., 2017). Cancer impacts physical, cognitive, and emotional aspects of life as well as other important body processes and functions through the harsh treatments necessary to rid the body of the cancer cells (Baxter et al., 2017). Treatments can cause one or more side effects including pain, fatigue, impairment in emotional functioning, anxiety, depression, insomnia, and body image (Loh & Jonsson, 2016). More consequences of cancer treatment can be balance and mobility problems, bladder and bowel issues, communication difficulties, cognitive problems, etc. (Alfano et al., 2017). These limitations, or side effects, can interfere with the patient's ability to be functional at work and participate in lifelong activities (Alfano et al., 2017).

Although cancer treatments are used to save lives, survivors are left with physical and psychosocial complications that can prevent engaging in everyday life activities and can result in a compromised quality of life (Baxter et al., 2017). These effects can make it hard for individuals LWBC to continue with their typical daily activities such as going back to work, self-care, leisure, social activities, etc. (Alfano et al., 2017).

Cancer is recognized as a chronic condition that has a draining impact on areas in a patient's life (Loh & Jonsson, 2016), which requires care beyond a medical standpoint. However, there is a lack of survivorship care including rehabilitation that can prolong the physical, cognitive, and emotional side effects of cancer (Baxter et al., 2017). Therefore, a broader psychosocial-emotional and occupational functioning model of care is needed, throughout the cancer continuum, that addresses occupational participation for reengaging with work, daily activities, and leisure (Loh & Jonsson, 2016). With the side effects of cancer negatively impacting an individual's quality of life, the use of rehabilitation including occupational therapy (OT), physical therapy (PT), and speech therapy (SLP) can help to reduce these impacts and improve the function of the individual (Stout et al., 2021). Cancer rehabilitation is defined as restoring the level of independence and functional ability that one had before cancer (Pergolotti, 2014). The ability to resume the performance of daily activities, work, and engagement in meaningful activities after cancer continues to be overlooked in rehabilitation (Loh & Jonsson, 2016).

The need for cancer survivorship rehabilitation is evident; however, many rehabilitation professions including OT are underutilized (Pergolotti, 2014). Physician unawareness and poor communication between fields lead to a lack of referrals needed to access care (Pergolotti, 2014). Evidence supports the use of rehabilitation to treat physical, cognitive, and performance impairments to manage oncology treatment-related symptoms (Stout, 2021). With the absence of screening and monitoring cancer patients for rehabilitation services, many of these symptoms and problems go unaddressed. Routine screening and referrals to rehabilitation services should be implemented across all oncology settings (Alfano et al., 2017).

For individuals LWBC, OT addresses health, well-being, and participation to enhance length and quality of life (Loh & Jonnsson, 2016; American Occupational Therapy Association

[AOTA], 2020). Utilizing this holistic approach, the person is focused on as a whole, rather than the isolated aspect, which addresses all aspects of cancer effects (AOTA, 2020). With the known benefits that OT can provide, there is a need to understand why services are underutilized in those LWBC, including exploring barriers to OT referral. Currently, researchers are conducting a systematic review exploring reported barriers to cancer rehabilitation from health care professionals' point of view; however, results are not yet determined (Cadmus-Bertram & Douglass, 2021). Understanding barriers provides background information on the referral process, though they do not improve utilization. Exploring supports provides implementable solutions to the overall problem of the lack of referrals to rehabilitation services for people LWBC (Boyden et al., 2010).

The purpose of this systematized literature review is to explore the factors surrounding referral to OTfrom healthcare providers in cancer care that include barriers as well as support to referral. The specific question used to guide this literature review is, "In cancer healthcare professionals, which factors influence the referral of individuals LWBC to rehabilitation services throughout their survivorship continuum?" The objective is to address why individuals LWBC are not receiving referrals to rehabilitation as well as what strategies can be implemented to receive referrals in the future.

Methods

The Model of Occupational-Participation for Cancer Survivorship (MOPCS), is an emerging model of survivorship care, augmented by the International Classification of Functioning (ICF) by the World Health Organization, that addresses the gap in the provision of services that focuses on the resumption of life occupations and engagement in meaningful activities throughout the survivorship continuum (Loh & Johnson, 2016). The MOPCS incorporates a number of critical areas for persons LWBC, such as distinguishing between health issues prior to cancer, health conditions throughout the disease, and health conditions after cancer has been eradicated (Loh and Johnson, 2016). The use of the MOPCS assisted in organizing thinking with regard to article inclusion for the supports and barriers of cancer rehabilitation referrals throughout the survivorship continuum.

Data Extraction and Synthesis

To begin the search process, a systematized approach was used that followed a sequential procedure with the elements of a systematic review including comprehensive searching, leveling of articles, quality assessment, and bias reporting. A grey literature search was conducted through PROSPERO and Trip Database. In collaboration with an expert in systematic reviews, a faceted search of indexed databases including; PubMed, CINAHL, Academic Search Complete, Medline, and PsychInfo was conducted. A hand search was used to accompany the original searches of Medline. The search criteria were bound by referral, the one main search term, followed by an extensive list of cancer, rehabilitation, and medical professional sub-terms. Filters were used to narrow the search which included 'date-range', 'language', and 'subject heading'. The search included all publications since 2011. We extracted data in order to compare and understand the presented outcomes. The full list of search terms used is listed below in Table 1. Database search results were collected and imported into Zotero (Version 5.0, 2021) software before transferring into Rayyan software where exclusion and inclusion criteria were handled (Ouzzani et al., 2016). The results from each search device were gathered, collected, and reviewed for duplicate entries. All citations and abstracts were reviewed by at least two independent reviewers. All citations that were accepted by the reviewers were included in a full-text review which was conducted by at least two of the same reviewers. Through both screening processes, a third reviewer handled and resolved any disagreements.

Inclusion/Exclusion Criteria

Studies were included if they (1) include persons living with/or beyond cancer, (2) include any age, race, and gender, (3) were in English, (4) include barriers and/or supports to referrals, (5) any international articles written in English, and (6) include one or more key terms. We excluded studies not reported in English, any studies prior to 2011, and if there was a lack of focus on cancer survivorship. Quality Assessment and Analysis In this systematized review, we analyzed the study sample, population, and setting, the level of evidence, and the quality rating. We described the level of evidence by using the Johns Hopkins Evidence-Based Practice Model which includes five levels of appraisal, as indicated in Table 2. Articles classified as levels 1-3 were used for the purposes of this review to reduce bias in the outcomes.

Procedures to Address Trustworthiness and Credibility

Researchers started using an audit trail at the beginning of the study that included index tracking of initial and final coding, and notes on decision-making to increase dependability and confirmability (Creswell, 2013). Collectively, the research team engaged in continual reflexive thinking by considering and challenging how biases and past experiences might influence data interpretation (Creswell, 2013). Additionally, both the first and last authors (K.P. & K.L), experienced qualitative researchers that performed the data analysis in the first Israeli study, did not actively code data for this study. They did supervise the other researchers during the analysis process so as to not influence or bias results from the first to second study. Various types of data were collected to assure triangulation and establish credibility including video recordings, transcriptions, and field notes from focus group discussions (Creswell, 2013). Member Checking occurred at the end of each focus group, by having note takers summarize discussions to the participants for changes, additional comments and for confirmability and to support credibility (Creswell, 2013).

Results

A database search was conducted, yielding a total of 862 articles that were imported into Zotero (Version 5.0, 2021) for deduplication, identifying 154 duplicate articles. There were 708 articles from database searching and 59 articles from hand-searching methods that were imported into the Rayann software for manual appraisal (Ouzzani et al., 2016). Due to the inclusion criteria, 657 articles were excluded and 53 articles were assessed for eligibility to answer the PICOT question. Fifteen articles met the full inclusion criteria from the database search. This process is outlined in the PRISMA Flow Chart depicted in Table 1, and Appendix G includes the article title, leveling of evidence, and findings relevant to this review as shown in Table 2.

In total, 15 articles were assessed for bias risk using the Risk of Bias table for Randomized Controlled Trial (RCT) and Non-RCT, as well as the Risk of Bias table for Before-After (Pre-Post) Studies with No Control Group (Higgens et al., 2016; National Heart Lung and Blood Institute, 2014). There were 12 articles that demonstrated low bias risk (Oldenburg et al., 2020; Marshall et al., 2019; Mousten et al., 2015; Silva et al., 2020; Nwosu et al., 2012; Wadhwa et al., 2018; Mertens et al., 2017; Low et al., 2018; Schenker et al., 2014; Johnston et al., 2021; Mousten et al., 2019; Feld et al., 2019), two articles demonstrated moderate bias risk (Weaver et al, 2018; Johnson et al., 2010), and one article demonstrated high bias risk. (Maiwald et al., 2021).

Four emerging themes including (1) the oncologists' perspectives on rehabilitation, (2) personal characteristics of patients, (3) characteristics of cancer (4) multidisciplinary communication, were consistently found to be related to referral to rehabilitation. All of the articles included in this review were related to referral to palliative care, and the database search revealed that there is little to no research related to the referral of patients LWBC to other areas of rehabilitation services.

Theme 1: Oncologist's Perspectives on Rehabilitation

Seven articles focused on the oncologist's perspective of rehabilitation. There were five articles that were Level III qualitative studies (Johnson et al., 2011; Nwosu et al., 2012; Weaver et al., 2018; Feld et al., 2019; Schenker et al., 2014), one was a Level IV quantitative (Meritens et al., 2017), and one was a Level III case-control (Oldenberg et al., 2020).

One of the barriers found was that many oncologists believed the care they were providing was sufficient, and they could treat the patients' needs on their own without any rehabilitation services (Weaver et al., 2018; Feld et al., 2019). Doctors claimed to have established a rapport with patients and knew the extent of their issues, but patients were most likely uninformed throughout treatment leading to a lack of knowledge of referral (Johnson et al., 2011; Nwosu et al., 2012). This has led to the idea of physicians' concern about burdening patients with extra treatment as they worry the patient might feel overwhelmed (Feld et al., 2019).

Authors from three articles indicated that physicians do not want individuals to experience or feel abandoned during treatment: one article was Level IV quantitative, one was a Level III multisite qualitative interview study, and one was Level III qualitative. Oncologists tend to worry about how patients will feel neglected throughout their treatment and how it could affect them (Schenker, 2014), even though these services can help with the transition to end-of-life care (Meritens 2017).

Theme 2: Personal Characteristics of Patients

Three articles found personal characteristics, including race, age, gender, education level, and socioeconomic status (SES) influenced the rate of referral to palliative care. All three articles were Level 3 articles; one was a quantitative study, one was a population-based cohort study, and one was a quantitative retrospective cohort.

One quantitative study revealed Black patients were less likely to receive palliative referrals than white patients (Lee et al, 2021). Researchers of a population-based cohort study demonstrated younger patients were more likely to be referred than older individuals and females received more referrals than males (Mosuten et al, 2015). Data from the same study showed those with higher levels of education had a higher rate of referral than those with lower levels of education (Mosuten et al, 2015).

Additionally, researchers of a quantitative retrospective cohort study found there was a disparity in both referrals to palliative care and attendance of services between members of low and high-socioeconomic-status groups. Members of lower SES received fewer referrals and were less likely to attend than their higher SES counterparts (Dalton et al, 2019).

Theme 3: Characteristics of Cancer

Five articles found that various characteristics of cancer, including specific symptoms, type of cancer, and stage of disease were related to patients' referral to rehabilitation services: two were Level III qualitative studies, one was a Level III Quantitative Retrospective Cohort study, one was a Level III retrospective review, and one was a Level III mixed-method study.

Researchers from these articles indicated that various symptoms, including nausea or vomiting, pain, gastrointestinal difficulties, and difficulty breathing were viewed by physicians as a reason to refer patients to palliative care (Johnson et al., 2010; Feld et al., 2019).

Malnourishment was a specific symptom that was related to earlier referral to palliative care than other symptoms patients experienced, as well as significant weight loss (Silva et al, 2020).

In addition to symptoms prompting physician referral to palliative care, the stage of cancer a patient was diagnosed with was also related to referrals. Patients with stage III and IV tumors were more likely to be referred to palliative care than patients with stage I or II tumors (Silva et al, 2020), and patients who received a cancer diagnosis two or more years prior were more likely to be referred than those who received a diagnosis more recently (Wadhaw et al., 2018). Specific types of cancer, such as breast cancer, were more likely to be referred to palliative care earlier than other types of cancer (Low et al, 2018; Wadhaw et al, 2018).

Theme 4: Multidisciplinary Coordination and Communication

Six articles indicated that there was a lack of multidisciplinary coordination and inter-service communication between oncology professionals and rehabilitation services: one was a Level II case-control study, one was a Level II mixed methods study, three were Level III qualitative studies, and one was a Level III mixed methods study.

An overarching finding from these studies was that there was insufficient communication between the professionals involved in caring for those LWBC, and the benefits of collaboration with other disciplines were not viewed to be worth the difficulties (Maiwald et al., 2021; Low et al., 2018).

A barrier to referral noted by two studies was that oncologists were not educated on the benefits that rehabilitation services may provide their patients nor the aspects that may qualify a patient for rehabilitation (Schenker et al., 2014; Nwosu et al., 2012). The authors of the two articles demonstrated a potential lack of formal education on rehabilitation services within medical programs (Weaver et al., 2018; Oldenburg et al., 2020). There was a low percentage of students in pediatric oncology fellowship programs who reported being required to have a rotation in palliative care services (Weaver et al., 2018). Additionally, students in medical school reported a lack of confidence in referring patients to rehabilitation services in terms of qualifications for rehabilitation and the benefits it can provide (Oldenburg et al., 2020).

Discussion

This systematized review considered the literature regarding the barriers and supports of referral of patients LWBC to rehabilitation services. Palliative care was found to be a prominent area of referral for patients LWBC compared with other rehabilitation services, such as physical or occupational therapy.

There is strong evidence characterizing the barriers to referrals due to the oncologists' views or beliefs on the subject. These barriers include a lack of knowledge (87.6%) and awareness (85.6%) of the cancer rehabilitation services and how they can benefit a patient throughout their treatment (Yang et al., 2014). These findings support the evidence from previous articles indicating these barriers prevent a patient from receiving optimal treatment. There is limited evidence supporting the idea of lessening the burden on patients to prevent them from thinking the oncologist gave up on their treatment.

There is strong evidence indicating that personal characteristics (including race, age, gender, education level, and socioeconomic status) contribute to lower rates of referral and subsequent poorer health outcomes for those with cancer (Lee et al, 2021, Mosuten et al, 2015). These findings suggest personal biases of providers who refer influence the rate of referral. Although it was found these characteristics hinder referral, previous literature did not find them to be a barrier to referral specifically, despite the indication that these characteristics resulted in general poorer health outcomes for those with cancer (Halpern et al., 2016). These poor outcomes could be related to a lack of referral.

There is strong evidence in the literature that the characteristics of cancer are a barrier to referral to rehabilitation services for patients LWBC. The diagnosis, prognosis, and symptoms of cancer were specific factors previously found in research to be barriers to referral (Hui et al., 2016; Lattanzi et al., 2010). These findings support the evidence from this systematized review and may indicate that patients who have early stages of cancer, good prognosis, or lack specific symptoms are overlooked when referring to rehabilitation services.

There was not any previous research indicating multidisciplinary coordination and communication as a barrier to referral to rehabilitation for those LWBC. However, the evidence from this review demonstrates that six articles addressed multidisciplinary coordination and communication as a common barrier to referral. One specific barrier noted in these articles includes insufficient communication between healthcare professionals regarding the treatment plan and patients' status. This novel theme should therefore be explored further in research to determine the impact it might have on the referral of patients to rehabilitation services.

Limitations

Limitations of the systematized review include the design and methodology of the individual studies. The articles were primarily Level 3, which is a lower level of evidence, and there were no Level 1 articles (Higgens et al., 2016; National Heart Lung and Blood Institute, 2014). Despite this limitation, all but one article were found to be high quality, justifying their inclusion in this review. Several measures were taken to ensure comprehension of search strategies, however, it is possible that relevant studies were overlooked, creating a publication selection bias.

Additionally, a few of the studies included specific groups in their sample, therefore limiting the generalizability to the larger population of oncology. Some examples of these specific groups include samples from large academic medical sites (Feld et al., 2019), well-developed palliative care programs (Schenker et al., 2014), or areas with cultural taboos surrounding palliative care (Low et al., 2018). The oncologists' perspectives regarding the referral of individuals LWBC to rehabilitation services within these studies may not generalize to the overall population of oncologists.

Implications

Referral to rehabilitation services is hindered by a variety of factors that lead to subsequent underutilization of rehabilitation services across the cancer care continuum. Further research is needed to determine how to improve rates of referral. No existing literature indicates when referral to rehabilitation services should be implemented to produce effective outcomes. Additionally, this review indicated a novel theme of referral. This should be further examined in future literature since it is a novel finding. Research guided by an occupational-based theory could be beneficial in discovering where in the cancer care continuum rehabilitation referral would yield the most advantageous results for people living with and beyond cancer.

Conclusions

Referral to rehabilitation services is underutilized across the cancer care continuum for individuals LWBC. Barriers to referral include cancer care providers' lack of education about OT services, personal characteristics (sociodemographic characteristics) of patients, characteristics of patient's cancer, and lack of multidisciplinary communication. These barriers are supported by other literature reviews. However, multidisciplinary communication was not found as a barrier to referral in other literature reviews and is considered a novel finding. Further education and research could aid in the reduction of barriers to referral for rehabilitation services for those LWBC.

PHASE II RESEARCH STUDY

Research Abstract

Those living with and beyond cancer (LWBC) have psychosocial and physical complications, compromising their quality of life (QoL). Occupational therapy (OT) offers a unique service promoting health, well-being, participation, and QoL. However, it has been revealed that OT services are underutilized in oncology care. Phase II of this international study explores the perspectives of healthcare professionals working with persons LWBC regarding the role of OT in oncology, as well as supports and barriers to OT referral. Data was collected through four focus groups with 17 participants. A multiple explanatory case study and a grounded theory approach were used to analyze data. Four overarching themes emerged, including "support for OT referral," "knowledge of patient client factors & side effects," "barriers to OT referral," and "participant context," along with ten sub-themes. The limitations of this research may impact generalizability and depth, such as a predominance of female participants. Future research should examine the impact of education on OT scope of practice on OT referral and recruit participants in diverse ways to address limitations. Addressing system barriers and advocating for the scope of OT may lead to more OT referrals in oncology.

Keywords: Cancer, referrals, OT, barriers, supports

Introduction

Cancer is now considered a chronic condition for many people, which can impact returning to function, participation, and quality of life (Hunter et al., 2017). While cancer treatments' primary focus is to eliminate cancer and prolong one's life, survivors often face residual physical and psychosocial complications that lead to a compromised quality of life (Baxter et al., 2017).

There is a strong need for rehabilitation services, specifically occupational therapy (OT), for those living with and beyond cancer (Baxter et al., 2017). Many individuals LWBC that are both in treatment or remission can experience adverse symptoms that influence their overall occupational performance and quality of life. The goal of OT is to maintain and restore function, reduce symptom burden, optimize independence, and improve the quality of life (Alfano et al., 2017). Rehabilitative and OT services are underutilized in oncology care despite the growing evidence and recommendations to regularly screen for the need for these services (Baxter et al., 2017; Stout et al., 2020).

Currenlty, there is a paucity of literature surrounding the referral process to OT in cancer care. To support proper referral practices, other healthcare professionals in cancer care need to understand the role of OT and the indications for appropriate referrals (Oldenburg et al., 2017). A lack of referral can stem from a lack of knowledge regarding OT's role in oncology and the lack of communication between providers and employers. These professionals can help coordinate work-based programs with cancer rehabilitation for optimal effectiveness (Alfano et al., 2017).

Some barriers that exist that impact referral to rehabilitation and OT services include a lack of knowledge of rehabilitation services by referral sources, understanding in who is appropriate for referral, a lack of rehabilitation services in oncology-based institutions or nearby communities, and a lack of infrastructure supporting an easier referral process (Pergolotti et al., 2019).

The purpose of this study was to investigate the perspectives of healthcare professionals in the United States who work with individuals LWBC regarding OT involvement in cancer care. Additionally, an overarching aim was to outline the current barriers and facilitators influencing referrals to OT during and after cancer treatment. The specific aims of this study were to explore the perspectives of healthcare professionals in the United States regarding 1) the role of OT in cancer care, 2) the need for OT services for cancer patients, 3) the current barriers to OT referral, and 4) what is needed to optimize referral.

Methods

Research Team

This study was conducted by seven graduate students studying OT at the University of Indianapolis while receiving support from two experienced qualitative researchers. Of our four focus groups, two were led by student Taylor Brown, one was led by student Alexandria Gilley, and one was led by researcher and data collector Khawla Loubani. All researchers were female and received training through a data analysis research course. Student researchers did not have any relationships established with participants prior to the commencement of the focus groups. At the beginning of the focus group, the scheduled interviewer explained their participation alongside Dr. Katie Polo in this research project. Dr. Katie Polo served as the principal investigator of this research study.

Research Design

The research coordinators conducted a study using a multiple explanatory case study, allowing compelling evidence to be formed from each case and compared for analysis (Yin, 2018). The exempt review was processed through Helsinki, the primary institution's IRB in Israel, and the University of Indianapolis IRB entered into a reliance agreement for data collection in the United States. All participants were asked to give consent to participate through Qualtrics.

Participants

Researchers utilized purposive sampling methods, including professional contacts and recruitment by phone, email, flier, social media, and word of mouth. This type of sampling method allows the researchers to select individuals and sites that can provide information, as well as participants that relate to the reason for the study and the research problem (Creswell, 2013). Participants consisted of those who met the following criteria: (1) currently working in oncology or cancer care, (2) professional as a nurse, oncologist, social worker, or physician's assistant, and (3) located within the United States. Our goal was to conduct four focus groups consisting of four to six participants, because this number is ideal for identifying themes and conducting a cross-case theme analysis (Creswell, 2013).

Data Collection

Data was collected through four focus groups, consisting of four to five participants. An interview guide consisted of ten open-ended scripted questions; see Appendix B for details. Open-ended questions in the interview guide allowed the interviewees to open up and share their responses (Creswell, 2013). Other data sources included Qualtrics survey and team member field notes taken during the focus groups. The focus groups were recorded and transcribed verbatim via Zoom and Google Meets©. There were no repeat interviews. The timing of the interview discussions averaged 33 minutes with a range of 30-36 minutes. Multiple research team members reviewed the focus group transcripts for accuracy. All participants completed a Qualtrics survey, including a consent form, before the start of the focus groups and demographic questions.

Data Analysis

Data was analyzed for this case study using a grounded theory approach, which includes three stages: (1) open coding to identify key elements, (2) axial coding to identify relations between the elements, and (3) selective coding to create propositions and a theory to explain the relations (Strauss & Corbin, 1990). During open coding, transcripts from the focus groups were used to form codes or categories, which then formulated a codebook. This codebook allows detailed descriptions, themes, and interpretations of the data (Creswell, 2013).

Seven researchers coded the data. Analysts and coders learned proper procedures for data analysis research through a data analysis research course. The data analysis process was supervised by two experienced qualitative researchers. The researchers individually coded the data from the focus groups, followed by collaborative coding in a group setting to derive themes with a consensus of at least five researchers. Data saturation was reached near the end of the second to last transcipt. Demographic data were analyzed using IBM SPSS Version 28 (IBM Corp., Armonk, NY).

Credibility and Trustworthiness

The use of multiple types of data collection, such as interview questions, detailed transcripts, and observations, permits the extensive amount of data collected from each focus group to be analyzed in great depth (Creswell, 2013). The research team used continual reflexive thinking throughout the process to assist in preventing personal biases thus increasing objectivity. Two experienced qualitative researchers reviewed and supported the data analysis process to ensure dependability and confirmability. Triangulation was used to establish credibility; the group collected various data methods such as video recordings, transcriptions, and field notes (Creswell, 2013). Note takers performed member checking by summarizing discussions to the participants for to confirm intent of discussions, supporting credibility and confirmability (Creswell, 2013). The writers of the study described the participants and setting in detail which enables readers to transfer information to other settings, allowing for increased transferability (Creswell, 2013).

Results

Participants

We recruited 17 professionals for this study: three oncologists, five nurse navigators, six nurses, and three social workers aged 30 to 66 years old. Participants' work experience ranged from 1 to 40 years. Demographics collected from the participants include age, gender, profession/specialization, practice state, prior referral to OT, possible collaboration with OT, and how collaboration with OT occurs. Participant demographics are shown in Table 1.

Findings

Four overarching themes emerged with subsequent subthemes. The theme “support for OT referral” consisted of subthemes (a) integration of OT into oncology; (b) knowledge of occupational performance; (c) knowledge of the scope of OT practice; and (d) ideas to support referral. The second overarching theme was “knowledge of patient client factors and side effects.” Theme three, “barriers to referral,” includes subthemes (e) insufficient awareness/knowledge of OT; (f) system barriers; (g) clinic barriers; and (h) patient barriers. The final theme, “participant context”, was separated into subthemes (i) profession; and (j) experience, interaction, and collaboration with OTs.

Barriers to Referral

Participants explained what is currently inhibiting the lack of referrals to OT in the oncology process. They were asked to describe their knowledge of the scope of OT, and several participant responses revealed a lack of understanding of the profession of OT and the role of OT within oncology. One participant was able to provide a limited description of OT, saying “I would say in general occupational therapy is…obviously a form of therapy…focusing on those signed motor skills versus the big muscle groups and bone….[and] job related movement.” A common topic of discussion was how PT and OT tend to get intertwined in that PT is more commonly known for their scope of practice. A participant shared, “I think I kind of intermix PT and OT a little bit. If I was asked to really give a specific difference and who they see I probably wouldn't get it correct.” Many expressed there is often confusion around the true description of the profession. One participant explained:

> You know I think, I think OT is a well-kept secret. Unfortunately, I think it's that you all don't market yourselves very well. Everybody knows what PT is. Everybody knows that. Unless we have something really specific, if somehow we happen to get referred to an occupational therapist, we don't know half of what you all do. You have a lot to offer but nobody knows you're nobody knows you're around.

Participants expressed barriers in the system, especially regarding the insurance process for receiving OT services. Patients may not be able to afford all of the services, which can limit the treatment they can receive. A participant stated:

> We pretty aggressively hate on cancer centers of America they do this “queen for a day” system, where they have, you see a nutritionist, a PT, an OT, a chiropractor, etc. You know, they have to see all these different subspecialties and then make you individually bill for all of them. And the patient actually can't afford to go to all those subspecialists. So it's got a bad reputation in cancer for that reason. That, you know, we try to do everything under one roof as much as we can.

A prominent sub-theme is that clinics have difficulty making referrals due to other priorities, or oncologists might be unsure which service to refer to. A participant shared, “We refer to physical therapy as a start, then occupational therapy as a second step or a parallel.” Individuals mentioned that it would be helpful to delineate clearly who handles what in the intervention process. It was also mentioned how physicians have several patients to see on a day-to-day basis and often do not even think of OT at the moment as a referral option. A participant reported:

> I'll just be really honest, clinic, clinics are busy. Physicians are having trouble seeing a lot of patients. The nurses, unfortunately, unless they've been tuned in the nurses, don't think of it. And I think they just haven't been exposed enough.

Oncologists also have to make referrals to these services, which can inhibit it from happening due to other priorities. Individuals voiced their opinion, “The biggest barrier was the oncologists. We shouldn't wait on giving someone a service that is necessary while they're getting treatment but it was definitely in my experience an afterthought.” Participants also shared how there may be a lack of OTs in the clinic, eliminating the ability to refer altogether. Patients often undergo several treatments at a time, which can drain their energy levels. Participants expressed how “the universal trait of all cancer patients is fatigue and overwhelmingly tiring on a physical, emotional front.” Patients also may not have the time or money to add other services to their schedule on top of what they are already doing. There may be a limited appointment window for these individuals, and adding another service can be overwhelming. A participant shared, “I think oftentimes when the patient is in the throes of treatment, it's hard for them to think about adding an additional appointment.” It was found that patients may also be more reserved when it comes to the need for OT or PT services and want to just focus on one treatment at a time. “But it seems more times than not patients are so focused, driven on one treatment to the next, which, that's their reality right now is “Hey, I need to do this to get to the next step. Do this chemo. Do a CT. Let's see how it is.” A participant explained how a lot of this can be due to a lack of awareness and resources on the patient side. Patients do not realize what else can help them as they are hyper-focused on other treatments. A participant explained:

> Some patients think that they've been through so much that they don't realize that they don't have to be in this kind of state; they can actually improve afterward as well some patients are thinking that this is their new normal. So we do want them to be able to do as much as they can on their own and improve.

The individuals expressed barriers limiting referrals to OT during the cancer survivorship continuum. Participants expressed a lack of awareness or knowledge of OT, patient barriers, and how clinics tend to have other priorities in the referral process.

Participant Context

Participants expressed varied levels of context for OT. All participants had some knowledge of OT as a profession based on their personal experiences, professional interactions, and collaboration with OTs. Personal experience with OT included knowing occupational therapists or OT students and/or use of OT services for themself or a family member. A participant reported, “My son was in OT when he was small so I'm familiar with that... then my sister is in OT school. So she often has to create different tools for people in certain situations. So that's what I know.” Participant context of OT also came from professional interaction and collaboration with OTs. Most of the participant context of OT came from professional experiences working with OTs. Participants reported having knowledge of OTs' work with sensory processing disorders in pediatric settings and some knowledge of OTs' role in oncology. One participant stated, “I do know the OT I worked with most closely when I was at radiation oncology. She helped a lot with neuropathy issues and lymphedema issues.” Additionally, a participant shared her experience with OTs helping patients post-mastectomy and post-node removal patients regain upper extremity function, “By working with the OT clinics, she was able to regain function, you know, have a sleeve that fit gets fitted for one actually, you know, regained use of her dominant arm, which was a huge deal for her.” Most participants relied on personal contact with OT as their source of knowledge for the scope of practice through family members receiving OT services rather than professional experience and being educated on OT’s presence and role in their setting.

Support for Referral

Participants expressed their current understanding of the purpose of OT as it relates to the oncology setting. The subtheme of knowledge of OT scope of practice was delineated into partial knowledge and sufficient knowledge based on participants' descriptions of the services OT provides. Some responses indicated that participants had only partial knowledge of the scope of OT, focusing on side effects in patients resulting from oncology treatment or the cancer process. The participants mentioned several side effects that might prompt referral to OT in their settings, including weakness, fine motor difficulties, fatigue, and peripheral neuropathy. It was also noted that referrals to OT are made to address the long-term side effects that cancer or oncology treatments may yield. One participant stated, “I refer to OT mostly for peripheral neuropathy and kind of assistance with tools like that... Generally, just again, trying to kind of assist with activities of daily living type things. But probably the neuropathy is the biggest referral.” Participants mentioned fatigue and neuropathy multiple times, though these are a small part of the OT scope of practice. Other participants provided more details regarding why they might refer to OT services within the oncology setting, indicating a sufficient knowledge of the scope of OT practice. It was noted that the side effects from cancer or oncology treatments often impact patients' daily activities, and a few participants discussed how specific side effects might relate to occupational performance deficits observed in patients. The participants demonstrated adequate knowledge of the profession of OT while also indicating an understanding of the impact that cancer treatments may have on their patient's overall function and engagement in occupations. It was reported that the impact of side effects was most often seen in patients' abilities to engage in activities of daily living and to function safely within the home environment. One participant stated:

> OT is a type of rehabilitation it's closely related to physical therapy but focuses more on task-oriented or real goal-specific things as opposed to generalizing strength training, for example, spoon use after stroke or swallowing efficiency, things like neuropathy or fatigue in cancer as opposed to the goal of having a general physical goal where like 30% of use back actually, having a focused goal with like an ADL purpose.

A few participants expressed a deeper understanding of the scope of OT within the oncology setting through the relation of side effects to occupational performance deficits. It was also noted that participants used clinical experiences to describe how side effects impacted the occupational performance of oncology experience, and this application of knowledge provides support for referral to OT based on the integration of knowledge and experience with patients. This second subtheme, knowledge of occupational performance, was also separated into partial or sufficient knowledge of occupational performance. Partial knowledge was signified by the description of side effects loosely tied to occupational performance, while sufficient knowledge involved comments describing the impact of side effects on patients' occupations. One participant explained, “I mean neuropathy can be as little as discomfort and walking or as much as writing with the pen or buttoning their shirt for balance issues.” The side effect that was emphasized as having a substantial impact on cancer patients was fatigue, as well as subsequent shortness of breath and weakness. These factors were noted to affect the functioning of the participants' patients negatively, and participants expressed that assistive devices are helpful in combating these side effects, indicating support for referral to OT services in those situations. Additionally, a few participants pointed out that it can be challenging to directly obtain information about changes in daily functioning from the patients. It was mentioned that family members often provide insight into the impact that side effects have on patients' daily lives. The participants' understanding of how to obtain information about patients' occupational performance supports the referral process, as it guides them in asking questions to the family members and the patients. One participant described this scenario, saying:

> I feel the family is usually where we hear that from. Usually, the family will say things like, you know I'm worried about them falling, um they're not eating like they should, they're not bathing well on their own, um they're not as active. So I feel like it's usually the family who will first make a comment about just their decrease in functioning.

Another prominent subtheme in support of OT referral is the integration of OT in oncology. The participants discussed processes currently in place at their facilities that promoted OT involvement in oncology patient care. It was expressed that many participants try to ask patients about any side effects that they might be experiencing to identify the need for OT services earlier. Several participants also mentioned that their facilities incorporated inpatient OT into the care plan so that patients could receive OT services while still in the hospital, as it was noted that appointments in outpatient following the hospital stay may be difficult for patients to attend for various reasons. One of the participants worked as a breast surgeon in a facility that had a revital program, which included an automatic referral as a part of the post-surgery protocol. The participant further described the program:

> So for me, we do refer all the post-surgical patients. And then we send them back during their survivorship period from my perspective because I'm the surgeon if they have continued range of motion issues and really the big thing we focus on is lymphedema.

Other participants mentioned that their facilities schedule OT evaluations alongside other services to reduce the need for patients to attend multiple appointments. It was noted that a new protocol had recently been enacted in which OTs would come into the infusion clinic to assess the need for OT while patients were simultaneously receiving other treatments. The participant at this facility stated:

> So we recently have really tried to make use of our partnership with one of our local groups that we refer to a couple of times in this conversation and so what I have agreed to do with them, that group is to have them actually, physically come into the clinic in our infusion room and do some assessing, talking to the patients directly without, you know, kind of with an agreement that if they see something, then they'll say something to us and we'll refer based on that. So, just kind of an extra set of professional eyes. They know what they're looking for, or what they're listening for in conversations.

In addition to identifying current processes supporting OT referral, the participants provided several suggestions to increase the referral of oncology patients to OT. This subtheme to support OT referral includes ideas to simplify and streamline the process of OT referral, as well as reduce the burden of OT appointments for patients. Several participants mentioned that coupling OT with other services, such as infusions or chemotherapy, could increase the utilization of OT services since it would address the issue of patients having multiple weekly appointments. It was also stated that providing co-treatments with PT may be beneficial for the same reason of reducing patient burden. A common suggestion among participants was to provide more specific outlines of what OT can contribute to the oncology process, such as through evidence-based case studies. One participant explained:

> Yeah, I think like you mentioned case studies where it's outside the box, and we know the general overview of what you do. But there's a lot more to it and when we see that, then it helps to think "Oh my gosh. Yeah, this patient I can use that."

Creating more specific resources for healthcare providers may increase confidence in their knowledge of OT scope of practice, which in turn can further increase referrals to OT services.

Knowledge of Patient Client Factors & Side Effects

Participants named many cancer treatment side effects that reduced patient occupational performance. Although client factors vary per client and are influenced by type of cancer, a typical client factor discussed by participants was fatigue. General fatigue inhibits patients from participating in the occupations they did prior to treatment, reduces performance, and interferes with socialization. One participant noted:

> One of the biggest issues is always fatigue, across the board is the fatigue, the energy loss. I think it's very dependent though on the cancer as well because if you're talking about head and neck cancer or you're talking about prostate cancer I mean it's very different.

A participant, who is a practicing surgeon, stated loss of motion and sensory changes occur as a result of cancer-related surgeries, like mastectomies and lymph node removals. These client factors reduce mobility and interfere with client function. Multiple participants reported weakness and lethargy as culprits for decreased occupational performance:

> I've had a couple of patients who just have a lot of weakness afterward and need to regain that strength…The weakness had caused her to lose activity as well. So she was even having some shortness of breath and things because she just hadn't been as mobile as she should have been.

Some client factors are long-term and impede client functioning after treatment is complete. Participants expressed that fatigue, 'chemo brain,' and neuropathy or pain often persist and interfere with occupational performance after treatment concludes. This theme highlights a need for interventions to improve occupational performance for cancer patients during and after treatment. The client factors and side effects noted by participants (fatigue, weakness, sensory changes, loss of range of motion, cognitive changes, pain, lymphedema) fall under OT's scope of practice.

Visual Diagram

A visual diagram was developed to capture the interrelated conditions (subthemes) and interconnections of the supports and barriers to OT referral in oncology care, as noted by the focus group participants, see Figure 1. While supports and barriers were prominent in this research study, it was also essential to understand the relationships between participant context, knowledge of client factors, and solutions to support referrals. The diagram simulates using the participant context and their knowledge of client factors to create solutions to support referrals. This will trickle into using the 'wrecking ball' to knock down the barriers, shown as the brick wall, most commonly reported by the participants to increase referral to OT.

Discussion

The current study was part of a more extensive international study between researchers in both Israel and the USA that explored the perspectives of healthcare professionals regarding the barriers and facilitators of OT referral for persons living with or beyond cancer. The current study had four aims: 1) to explore the perspectives of healthcare professionals in the USA regarding the role of OT in cancer care, 2) to explore healthcare professionals' knowledge of the need for OT services for cancer patients, 3) to understand the current barriers for referrals to OT from healthcare professionals' perspectives, and 4) to explore what is needed from healthcare professionals perspective to optimize referral of patients to OT.

The outcomes of this study have provided further evidence that there is room for improvement in the referral of OT in oncology care in the United States. Through multiple focus groups, four themes were commonly observed; “support for referral,” “barriers to referral,” “knowledge of patient client factors/side effects,” and “participant context.” Participants throughout the focus groups explained their prior experiences with OT referral in oncology care while also describing briefly what OT services provide for oncology care. This information produced the subthemes "Integration of OT in Oncology" and "Knowledge of the Scope of OT Practice." The subtheme "Knowledge of the Scope of OT Practice" comprised two types of knowledge: partial knowledge and sufficient knowledge.

An intersection between the theme "knowledge of patient client factors/side effects" and the subtheme "knowledge of occupational performance" was identified a few times throughout data analysis, indicating that some participants inadvertently had partial knowledge about how patient side effects from cancer cause a decline in occupational well-being and performance. The other intersection that commonly arose throughout our data analysis was between "knowledge of patient client factors/side effects" and the subtheme "knowledge of the scope of OT practice". The results from this intersection show most participants had partial knowledge of the scope of OT practice due in part to the experiences and side effects their patients experienced in cancer treatments.

The current literature supports the findings of this study. Previous researchers identified the underutilization of OT services in oncology care regardless of growing evidence for the need for rehabilitative services. Data from this study found an underutilization of referrals to OT services for patients LWBC for a variety of reasons (Baxter et al., 2017; Stout et al., 2020). The primary reason for this lack of referral is a lack of understanding of OT's scope of practice and role within oncology. This finding is supported by previous literature which argues that healthcare professionals must understand OT's role in oncology to support proper referral practices (Oldenburg et al., 2017; Alfono et al., 2017). Data from this study indicates that the lack of occupational therapists available in outpatient oncology clinics and integrated into inpatient oncology settings is a barrier to OT referral. This indication is supported by Pergolotti et al.(2019), who cite the lack of services in oncology-based institutions or nearby communities as a barrier to referral.

The current literature did not discuss patient barriers that directly impact referral to OT. Data from this study cites lack of time and resources as patient-specific barriers that prevent referral to OT. Many participants discussed patients being inundated with follow-up appointments and time, transportation, and patient energy as deterrents for referral.

Limitations

The limitations of this research may impact generalizability and depth. The predominant participation of individuals from the nursing field, with a scarcity of medical doctors such as oncologists and surgeons, introduces a possible bias that restricts the applicability of findings to a broader medical context. The overrepresentation of female participants adds another layer of limitation, potentially skewing the results if gender-related nuances exist in the topic under investigation. However, data saturation was achieved by the end of the third focus group due to having consistent data over multiple samples to conclude. The use of Google Meets© as a platform, combined with a group setting, may have inadvertently constrained the participants from freely expressing conflicting views or opinions that involve professionals from other disciplines. This limitation could compromise the diversity of perspectives essential for a comprehensive understanding of the subject matter. As such, it is crucial to acknowledge these constraints when interpreting the study's outcomes and to recognize the need for more diverse and extensive participant inclusion in future research endeavors. In addition, it is possible that focus group members felt unable to state opinions in a group setting due to having multiple professions or colleagues present. To offset this possible limitation, member checking was completed at the end of each focus group in which note-takers discussed the findings to allow for additional comments and changes and confirmability and credibility (Creswell, 2013).

Practice Implications

Throughout our interviews with oncology professionals, a common topic of underrepresentation and weak marketing of the OT profession was mentioned. Marketing allows professionals and consumers to function together and increase consumer satisfaction with products and services. This could increase understanding and knowledge of the scope of OT practice to improve referrals. A way to achieve this would be to create resources describing OTs' roles and services for other healthcare professionals to reference daily. These resources could also model methods of proper referral through the provision of patient examples detailing which symptoms warrant OT referral, as well as a list of clinics with available OT practitioners in the area.

Future research should further examine and explore the impact of education for OT referral sources surrounding OT’s scope of practice. Specifically, if referral sources received education to OT services, does this impact referral rate and access to OT services. Future studies should recruit in different ways and for a more extended period of time to gain more oncology professionals' perspectives to address the limitations of the current study's results. Addressing barriers to referral, including streamlining referral processes and easing the burden of multiple appointments for patients, as well as providing training and resources regarding the scope of OT and indications for referral may lead to more OT referrals.

Conclusion

This study highlighted prominent themes discussed among oncology professionals regarding barriers and facilitators of OT referrals. There are barriers to OT referral within the oncology setting related to oncology providers' lack of knowledge of services, lack of education on referral processes, and lack of accessible therapy services. These findings are supported by previous literature; however, this study also contributes novel information concerning patient-specific factors noted as barriers to the OT referral process. Education regarding the scope of practice of OT through OT based case studies will address initial barriers to OT referral within oncology settings.

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Appendix A

Table 1

Demographic data

Participant	Age (Yrs.)	Education level	Profession	Specialization / Department	Practice Setting	Years in cancer care	Collab. with OT	Active Referral to OT
1	47	MD	Med	Breast Surgeon	Academy	15	Yes (often)	Yes
2	66	MA	Nu	Clinical Research Coordinator	Community	23	No	No
3	60	BA	Nu	Thoracic Oncology Nurse Navigator	Other	40	Yes (sometimes)	Yes
4	65	MA	Nu	Registered Nurse Abstractor	Other	40	No	No
5	35	Associates's	Nu	Manager, Nursing Services	Community	4	No	Yes
6	54	Associate's plus a year towards BSN	Nu	Primary Clinic Nurse	Community	24	No	Yes

7	45	BA	Nu	Clinic Nurse	Community	1	No	No
8	-	-	Med	Oncologist	-	-	-	-
9	-	-	Nu	-	-	-	-	-
10	30	MA	SW	Oncology Social Worker	Hospital	4	No	Yes
11	56	MA	SW	Social Worker	Hospital	7	No	No
12	38	MD	Med	Medical Oncologist	Hospital	7	Yes (sometimes)	Yes
13	36	MA	SW	Program Manager	Community	8	No	No
14	54	BA	-	-	-	-	-	-
15	49	BA	Nu	Nurse Navigator	Community	15	No	Yes
16	43	Associate's	Nu	Breast Navigator	Hospital	10	Yes (sometimes)	Yes
17	47	Med	Nu	-	-	-	-	-
Mean (SD) Median (IQR) N %	Mean (SD) = 48.43	BA =4 (23.5%) MA= 5 (29.4%)	Nurses- 10 (58.8%)		Hospital= 4 (23.5%) Community= 6(35.3%)	Median (IQR) 10 (7-23)	Yes = 4 (23.5% (No= 9 (52.9%)	Yes = 8 (47.1%) No= 5 (29.4%)

	(11.31) Range= 30-66	MD = 2 (11.8%) Associate=3 (17.6%)	Social workers 3 (17.6%) MD =3 (17.6%)		Academy =1 (5.9%) Other=2 (11.8%)			

Note. Three participants had missing demographic data. We attempted to contact them after the interviews to complete the missing information but were unable to reach them. All participants were women, except participants 8 and 12 were men.

Med=Medicine; Nu=Nursing; SW=Social Work.

Appendix B

Table 2

Interview Guide

Interview Guide	
Study Aims	***Interview Questions Relating to Aims***
Aim 1: Explore the perspectives of healthcare professionals regarding the role of occupational therapy to the care of cancer patients.	What do you know about occupational therapy in general?
	What do you know regarding occupational therapy's role in oncology?
Aim 2: Explore healthcare professionals' knowledge of the need for occupational therapy services for cancer patients.	How does cancer affect your patient's daily functioning and activities of daily living (ADL)?
	What are the signs and/or indicators to refer your patients to occupational therapy?
	What limitations in your patients' daily functioning might prompt you to refer to occupational therapy?
	What kind of functional impairments do your patients have?
	How does cancer affect patients' daily functioning/routines?

Aim 3: Understand the current barriers to occupational therapy referrals from healthcare professional's perspectives.	What are the reasons that cancer patients are not referred to occupational therapy?
Aim 4: Explore what is needed to optimize referrals to occupational therapy.	What do you think is needed to optimize the referral of your patients to occupational therapy?
Additional Questions	Is there anything else you would like to share?

Note. The interview guide is sectioned into two different columns; the left colum indicates the study's specific aims while the right colum indicates interview questions that correspond to the study aims.

Appendix C

Figure 1

Visual Diagram of Supports and Barriers of Referral to Occupational Therapy